

AD_____

Award Number: DAMD17-00-1-0705

TITLE: Improving Implementation of Screening and Eye Examinations for Diabetic Retinopathy

PRINCIPAL INVESTIGATOR: Robert A. Goldstein, M.D., Ph.D.

CONTRACTING ORGANIZATION: Juvenile Diabetes Foundation, Intl
New York. New York 10005-4001

REPORT DATE: August 2001

TYPE OF REPORT: Final Proceedings

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

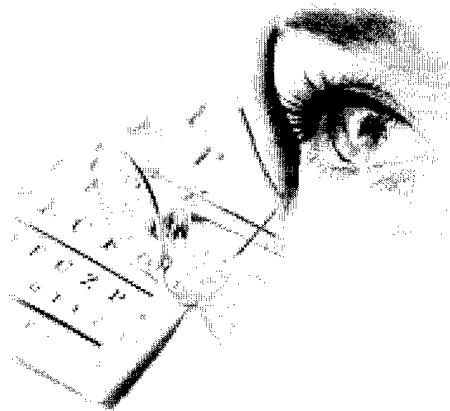
20010724 060

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 074-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

1. AGENCY USE ONLY (Leave blank)	2. REPORT DATE	3. REPORT TYPE AND DATES COVERED	
	August 2001	Final Proceedings (1 Sep 00 - 31 Aug 01)	
4. TITLE AND SUBTITLE Improving Implementation of Screening and Eye Examinations for Diabetic Retinopathy			5. FUNDING NUMBERS DAMD17-00-1-0705
6. AUTHOR(S) Robert A. Goldstein, M.D., Ph.D.			
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Juvenile Diabetes Foundation, Intl New York, New York 10005-4001 E-Mail:			8. PERFORMING ORGANIZATION REPORT NUMBER
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012			10. SPONSORING / MONITORING AGENCY REPORT NUMBER
11. SUPPLEMENTARY NOTES			
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited			12b. DISTRIBUTION CODE
13. ABSTRACT (Maximum 200 Words)			
14. SUBJECT TERMS Diabetic Retinopathy, eye screening			15. NUMBER OF PAGES 45
			16. PRICE CODE
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited



workshop on

Implementation of

Screening and Eye Exams for Diabetic Retinopathy

Proceedings Report

sponsored by

Juvenile Diabetes Research Foundation International (JDRF)

Agency for Healthcare Research and Quality (AHRQ)

American Diabetes Association

National Eye Institute

National Institute on Diabetes and Digestive and Kidney Diseases

U.S. Army Medical Research and Materiel Command

U.S. Department of Veterans Affairs



organized by

Research Triangle Institute

☒ Contents

Acknowledgments	1
Executive Summary	2
Introduction	5
Findings and Recommendations	7
Public Education	7
Access to Care	9
Quality of Care	10
Suggested Activities and Recommendations	11
Workshop Presentations	
Session I: Introduction to the Key Issues	13
Current Practice in Screening and Eye Exams for Retinopathy	13
Patient Population and Patient-Physician Relationship Issues	14
Cost-Effectiveness Issues: Ending Blindness from Diabetic Eye Disease	14
Role of New Technology in Enhancing Patient Access to Eye Exams	15
Session II: Patient Population and Patient-Physician Relationships	16
Perspectives on Care	16
Eye Exams and Their Relationship to the Progression of the Microvascular Complications in a Cohort of African Americans with Type 1 Diabetes	17
Patient-Physician Relationships in the Diabetic American Indian Population	18
Patient-Physician Relationships in a Diabetic Native Hawaiian Population	19
Approaches to Diabetic Retinopathy Screening and Prevention in Inner City Populations	20
Demographic Features Predicting Compliance with Recommendations for Annual Retinal Screening	21
A Best-Case Scenario: A Hypothetical Patient's Optimal Clinical Management to Prevent Progression of Retinopathy	21

Session III: Cost-Effectiveness Issues	22
Eye Exams for Diabetic Retinopathy as a Performance Measure of Quality: Findings from a Local Practice Improvement Project	22
Using Health Economic Information to Inform Health Policy and Decisions	23
A Public-Private Partnership to Increase Eye Exam Rates for Medicare Beneficiaries with Diabetes	24
Keynote Presentation: Improving the Care of Patients with Diabetes	24
Session IV: Role of New Technology in Enhancing Patient Access to Eye Exams	25
Implementation of Telemedicine Evaluation of Diabetic Retinopathy in a Prison Setting	25
Value = Quality/Cost: The Value of Telemedical Diabetic Retinopathy Evaluation	26
Telemedicine-Based Diabetic Retinopathy in the American-Indian Community in California	27
Session V: Summary	28
Session I	28
Session II	29
Session III	29
Session IV	29
Appendix A: Workshop Agenda	31
Appendix B: Workshop Participants	34

Acknowledgments

The “Implementation of Screening and Eye Exams for Diabetic Retinopathy” workshop was convened by the Juvenile Diabetes Research Foundation International (JDRF). JDRF thanks the Agency for Healthcare Research and Quality for providing the founding grant for this meeting, and the following agencies for their co-sponsorship: the National Eye Institute, the American Diabetes Association, the U.S. Army Medical Research and Material Command, the U.S. Department of Veterans Affairs, and the National Institute of Diabetes and Digestive and Kidney Diseases.

JDRF also expresses special thanks to the following individuals for their key roles in this meeting: Lloyd M. Aiello (Beetham Eye Institute); Daniel Stryer (AHRQ); Daniel Winfield, Susan Brown, and MaryBeth Branigan (Research Triangle Institute); Gayla Elder-Leake (NIDDK); and Megan Pace, Leanne MacNamee, and Colleen Reilly. Lastly, JDRF thanks all of the speakers and workshop attendees for their efforts in making this a productive meeting.

Executive Summary

Diabetic retinopathy is the leading cause of blindness in working-age adults today. Fortunately, 90% of this vision loss is preventable with early screening and treatment. Because the number of people with diabetes is expected to double in the next 30 years, it is vital that effective strategies are implemented now to improve retinopathy screening rates.

In an effort to confront this problem head on and address the challenges of promoting screening from a health services research perspective, the Juvenile Diabetes Foundation International—along with the National Eye Institute, the National Institute of Diabetes and Digestive and Kidney Diseases, and other sponsoring agencies—convened the Implementation of Screening and Eye Exams for Diabetic Retinopathy Workshop on February 27 and 28, 2001, at the campus of the National Institutes of Health in Bethesda, Maryland. The complete workshop agenda is included in Appendix A of the Proceedings Report.

Approximately sixty people attended the workshop, representing patient groups, professional organizations, government agencies, insurers, health care plans, and public policy makers as well as researchers. A complete list of workshop participants is included in Appendix B of the Proceedings Report.

Three specific areas were addressed at the workshop:

- Epidemiology and the various approaches that may be required to implement change
- Cost-effectiveness issues and how they affect the provision of eye care
- The impact and current use of telemedicine and other new technologies in providing retinopathy screening and eye exams

The two-day meeting was comprised of five sessions and included a keynote presentation and a postworkshop discussion group. A complete account of all the presentations is included in the Workshop Presentations section of the Proceedings Report.

In Session I, four presentations provided an introduction to the workshop's key issues. Topics included the following:

- Current practices in screening and eye exams for diabetic retinopathy
- Patient population and patient-physician relationship issues
- Cost effectiveness of screening practices
- The role of new technology in patient access to eye care

In Session II, seven case studies addressed issues related to patient populations and the patient-physician relationship as it affects access and quality of care. Topics included the following:

- An overview of different perspectives on care
- The use of demographic features to predict compliance with annual eye exam recommendations. Specific focus was given to African American, American Indian, Native Hawaiian, and inner-city populations
- A best-case scenario detailing a hypothetical patient's optimal clinical management to prevent progression of retinopathy

In Session III, three case studies examined cost-effectiveness issues related to retinopathy screening. Topics included the following:

- Findings from a local practice improvement project
- The usefulness of economic health information with regard to public health policy and decision making
- A public-private partnership developed to increase screening rates among Medicare beneficiaries

In Session IV, three case studies explored the role new technology plays in enhancing patient access to retinopathy screening and evaluation. Topics included the following:

- The implementation of telemedicine evaluation in a Texas prison setting
- A new telemedical evaluation service designed to access patients in the primary-care setting
- Telemedicine-based screening programs in the California American Indian community

In Session V, summaries from each session moderator were presented.

Finally, a postworkshop roundtable was organized to review, define, and prioritize key recommendations generated from the sessions. Participants were divided into three groups and directed to focus on developing strategies in the arenas of public education, access to care, and quality of care. The following suggestions emerged as the most significant and potentially effective ways to implement change in each area.

Public Education

The panel recommended the following action items regarding public education:

- Prevent diabetes and diabetes-related vision loss, i.e., retinopathy
- Identify and define the target audience for screening programs
- Develop novel methods of communication
- Improve patient education about diabetes, retinopathy, and treatment options
- Emphasize the importance of cultural awareness in screening plans
- Promote better doctor-patient relationships that encourage one-on-one treatment approaches and engender trust
- Understand the value of community-based approaches to education and screening

Access to Care

The panel recommended the following action items regarding access to care:

- Introduce and expand the use of telemedicine capabilities to provide better access to patients
- Bring retinopathy screening into the community and to the patients
- Involve the primary-care physician in the process, either through patient education or screening
- Explore the possibility of Internet-based care options
- Address economic factors and incentives related to screening rates and programs

Quality of Care

The panel recommended the following action items regarding quality of care.

- Simplify screening processes
- Obtain current patient data
- Develop comprehensive methods for record keeping
- Create systems to identify and eliminate errors of omission and commission
- Make eye exams a regular part of physical exams
- Improve awareness and communication regarding screening among the medical community, including primary-care physicians, internists, and diabetologists
- Explore the effectiveness of involving nurse care managers and practitioners more intensively in patient care and follow-up

Suggested Activities and Recommendations

The following specific action items emerged from the roundtable discussions. If implemented, these strategies will have a direct impact on the care that is delivered to patients. Ultimately, they will positively affect the outcomes of patients with diabetic retinopathy by addressing specific patient needs and identifying potential barriers to screening and implementation.

1. Evaluate current public education programs with a diabetic retinopathy component to ensure that any follow-up projects do not duplicate existing programs. Evaluation can be enhanced through interviews with leaders of current programs (like NEI, NIDDK, JDRF, and ADA) to create a compendium of programs.
2. Review and coordinate a HCFA Medicare Diabetes Eye Exam program; for example, a pilot study proposal that could be implemented with its state Peer Review Organizations (PROs). This could help determine the effectiveness of similar programs in promoting eye exams and education if expanded for use as a model in other target areas. It could also garner data to measure any increase in the screening rate when resources are dedicated to improvement. And finally, it would help create a state-based PRO implementation toolbox that would help disseminate pilot study best practices.
3. Create a demonstration project with JDRF to further examine the use of telemedicine in retinopathy screenings.
4. Ascertain the current level of acceptance for and use of the standard diabetic retinopathy/macular edema progression rating scale with a long-term goal of simplifying the scale and promoting its use and understanding among screening providers.
5. Explore the possibility of converting the progression ratings scale into a single-digit, quantifiable “lab test,” along the line of a cholesterol test. This would maximize its usability throughout the medical community and make it applicable in a variety of situations, including ICD-9.

Introduction

Diabetic retinopathy is the leading cause of blindness in working-age adults today. It is characterized by vision impairment or blindness caused by blood or fluid leakage into the vitreous, fluid-induced swelling of the macula, and occasionally retinal detachment. Patients can experience a loss of field integration, an alteration in binocular vision, and losses in resolution, contrast sensitivity, and color discrimination. Vision degradation is often very gradual; however, if scarring occurs, it can lead to detachment—a condition that rapidly results in blindness.

Approximately 90% of this vision loss is preventable with early screening and treatment. Unfortunately, less than 50% of all patients at risk are currently accessed into an appropriate eye care program and are receiving the recommended screening. Because the number of people with diabetes is expected to double in the next 30 years, it is vital that effective strategies are implemented now for battling what may become a major public health epidemic in the near future.

In an effort to confront this problem head on and address the challenges of promoting retinopathy screening from a health services research perspective, the Juvenile Diabetes Foundation International—along with the National Eye Institute, the National Institute of Diabetes and Digestive and Kidney Diseases, and other sponsoring agencies—convened the Implementation of Screening and Eye Exams for Diabetic Retinopathy Workshop on February 27 and 28, 2001, at the campus of the National Institutes of Health in Bethesda, Maryland. (For the complete workshop agenda, see Appendix A.)

The target audience for this meeting was “change agents”—individuals or groups who could shorten the cycle of outcomes improvement by working together. Approximately sixty people attended the workshop, representing patient groups, professional organizations, government agencies, insurers, health care plans, and public policy makers as well as researchers. (For a complete list of workshop participants, see Appendix B.)

Three specific areas were addressed:

- Epidemiology and the various approaches that may be required for different patient groups, including patient-physician relationship issues, and how these approaches could help implement change.
- Cost-effectiveness issues and how they affect the provision of eye care.
- The impact and current use of telemedicine and other new technologies in providing retinopathy screening and eye exams.

The two-day meeting was comprised of five sessions and included a keynote presentation and a post-workshop discussion group. (For a complete account of all the presentations delivered at the workshop, see the Workshop Presentations section.)

- In Session I, four speakers provided an introduction to the workshop’s key issues. First, an overview of current practices in screening and eye exams for diabetic retinopathy was presented, followed by a briefing on patient population and patient-physician relationship issues. Next, various topics regarding cost effectiveness of screening practices were explored, followed by an overview of the role that new technology plays in enhancing patient access to eye care.
- In Session II, seven case studies were presented exploring a variety of issues related to patient populations and the patient-physician relationship, particularly as it affects access

and quality of care. An overview of different perspectives on care was given, along with a description of different demographic features used in one study to predict compliance with recommendations for annual eye examinations. Specific focus was given to African American, American Indian, Native Hawaiian, and inner-city populations. Finally, a best-case scenario was presented detailing a hypothetical patient's optimal clinical management to prevent progression of retinopathy.

- In Session III, three case studies were presented examining cost-effectiveness issues as they relate to retinopathy screening. In the first study, findings from a local practice improvement project were reported. The second study addressed the usefulness of economic health information when it comes to informing public health policy and decision making. The last study explored a public-private partnership developed to increase screening rates among Medicare beneficiaries.
- In Session IV, three case studies were presented exploring the role new technology plays in enhancing patient access to retinopathy screening and evaluation. The first study took a unique look at the implementation of telemedicine evaluation in a Texas prison setting. The second study described a new telemedical evaluation service designed to access patients in the primary-care setting, and the third reviewed telemedicine-based screening programs in the American Indian community in California.
- In Session V, 10-minute summaries from each session moderator were presented.
- Finally, a 2-hour postworkshop roundtable was organized with some of the participants to review, define, and prioritize key recommendations generated from the sessions.

The goal of the workshop was to provide an overview of retinopathy examination and screening practices and to develop recommendations for the health service community in the following areas:

- Strategies for public education to increase the rate of eye exams
- Strategies for improving access to care to increase the rate of eye exams
- Strategies for improving quality of care in order to reduce sight loss and prevent blindness

If implemented, these strategies will have a direct impact on the care that is delivered to patients. Ultimately, they will positively affect the outcomes of patients with diabetic retinopathy by addressing specific patient needs and identifying potential barriers to screening and implementation.

The specific recommendations and action items that emerged from these sessions, and in particular from the postworkshop roundtable, are detailed in the following section.

Findings and Recommendations

Following the workshop, a select group of participants joined in a roundtable discussion of the ideas and issues raised during the meeting. The postworkshop participants were divided into three groups and asked to review, define, and prioritize the key recommendations generated by the speakers. Each group was directed to focus on developing strategies in the arenas of public education, access to care, and quality of care. The following suggestions emerged as the most significant and potentially effective ways to implement change in each area.

Public Education

The panel recommended the following action items regarding public education:

- Prevent diabetes and diabetes-related vision loss, i.e., retinopathy
- Identify and define the target audience for screening programs
- Develop novel methods of communication
- Improve patient education about diabetes, retinopathy, and treatment options
- Emphasize the importance of cultural awareness in screening plans
- Promote better doctor-patient relationships that encourage one-on-one treatment approaches and engender trust
- Understand the value of community-based approaches to education and screening

Prevention of blindness from diabetic retinopathy is crucial. Over the past 10 years, research has confirmed that vision can be preserved through regular eye screening and early treatment. As we seek better ways to increase and improve screening rates, patient access to care, and quality of care, however, we must not lose sight of the greater goal, which is to prevent diabetes. This fundamental crusade is fought daily by organizations like the Juvenile Diabetes Foundation, the National Institute of Diabetes and Digestive and Kidney Diseases, and the American Diabetes Association, and it lies at the heart of efforts like this screening and eye exam workshop. Because it is anticipated that the number of people with diabetes will double in the next 30 years, it is critical that we outline and establish successful prevention strategies now.

We can do this by identifying and defining different target audiences for screening programs. We know that certain ethnic groups are more at risk for retinopathy-related vision loss because of a greater propensity for developing diabetes. These groups include Native Hawaiians and Native Americans. In other cases, different socioeconomic factors can inhibit screening and treatment. For example, low-income, inner-city patients may not have adequate health care or insurance, but they may just as likely miss screening opportunities because of lack of co-pay or transportation problems. Age, insurance status, diabetes type, and cultural beliefs are just a few of the factors we might consider when determining who could benefit from targeted screening programs. And while it is clear that one system will not be effective in recruiting all patient populations, even a small effort could have a significant effect on exam rates if properly focused.

Once target groups have been identified, it is important to find and employ effective means of communicating screening information to them. Obvious candidates include primary-care physicians and eye-care providers. However, we have learned that many patients do not arrange for screening even after their physicians urge them to do so. It is apparent that they need to hear the message more than once and, most likely, in a variety of ways. Possibilities include public

service announcements; television and radio commercials; print ads, flyers, and brochures; and outreach activities in community areas like churches and grocery stores. These approaches target exposure to large groups of people, but we must also explore methods for communicating to individuals. For example, Aetna sent a single postcard to patients reminding them about the importance of eye exams. This mailing merited a 10% increase in screening rates. Other ideas include phone calls or the use of computerized reminders to encourage screening. A variety of specific, targeted approaches promises the best chance of reaching the most people.

In order for these efforts to be effective, however, patients need to be better educated about diabetes, retinopathy, screening, and treatment. Although this type of information is usually a key component of the messages and reminders we disseminate, many patients require more personal, one-on-one interaction. We know that some patients with diabetes are deterred by the belief that vision loss is inevitable, that screening is unpleasant, or that treatment is painful and expensive. Others think that because they have no symptoms, they are not at risk. Some patients mistakenly believe they have been “screened” because their primary-care doctor looked at their eyes during a routine physical examination. It is imperative that we clear up these sorts of misconceptions and get the facts out to the public.

One of the most powerful keys to effective education centers on the importance of cultural awareness when treating different patient populations. The values, beliefs, and attitudes held by various ethnic groups can greatly affect how patients respond to education and treatment. For instance, many Native Americans are uncomfortable with doctors’ repeated requests to keep written records of their diabetes management. In Hispanic communities, female family members may place low priority on their own health in deference to caring for their families. Asian Americans come from a culture that reveres elders, so they may have difficulty communicating with younger Western physicians. And in Native Hawaiian communities, where it is unseemly to draw attention to one’s self, medical care may be avoided until a condition is severe or complicated. We can ensure that our efforts will meet with greater success by taking cultural factors into account; however, in order to do so, care providers will need to be educated first.

One of the best ways to ensure effective communication is to promote strong doctor-patient relationships. Many efforts fail because of lack of trust. Doctors can build better relationships by spending adequate time with patients, learning about family and community influences, considering cultural factors, and encouraging a two-way dialogue about health management and care. Patients respond better when they are not subjected to a “one size fits all” approach. They are often encouraged to take a personal interest in their own health care and are more motivated to manage their diabetes when they feel a connection with their care provider. Occasionally, this trust factor becomes apparent in a patient’s interaction with another member of the medical staff, for example, in the rapport with a nurse. This type of relationship can still be a very effective venue for the dissemination of medical information, like the importance of eye exams.

Finally, it is important to understand the value of community-based approaches to education and screening. Patients may garner more social support and awareness regarding retinopathy screening when the message is targeted to entire communities. One Michigan-based prevention program took place in African-American churches and concluded that an intensive education program, coupled with rigorous follow-up, could indeed reduce the risk factors associated with diabetes, including vision loss. In another study targeting African-American Type I patients—the “New Jersey 725”—the results clearly underscored the need for simple, accessible, community-based screening opportunities.

Access to Care

The panel recommended the following action items regarding access to care:

- Introduce and expand the use of telemedicine capabilities to provide better access to patients
- Bring retinopathy screening into the community and to the patients
- Involve the primary-care physician in the process, either through patient education or screening
- Explore the possibility of Internet-based care options
- Address economic factors and incentives related to screening rates and programs

At present, only about 50% of all diabetic patients are involved in an appropriate eye care program. With the advent of telemedical technology, we have an unprecedented opportunity to break down access barriers and get screening into the community. Telemedicine is currently being used successfully in a number of programs, including one in the California Indian Health Programs and another in a Texas Department of Justice regional medical facility. An unexpected benefit of telemedicine is the opportunity it affords to patients to review their own computerized retinal images. This tends to empower them to become more involved in their own health care. Of course, such heavy reliance on an automated device will demand continued surveillance and evaluation. Some issues will pose challenges, such as reimbursement, licensure, quality of care, and cost. But the inevitable generational shift over the next few decades will no doubt change the nature of health care delivery, as more and more patients become comfortable with automated systems.

Whether we are using telemedicine or conventional screening techniques, it is imperative that we make an effort to offer expanded screening options to patients. It is evident from low screening rates that relying on patients to take the initiative and make the first (or even second) move is ineffective. Alternative approaches are surfacing, however. In one program, patients who came in for regular doctor appointments were offered same-day screening. Other practices experienced improved screening rates when appointments were made available in the evenings and on weekends. Tackling the problem from this angle may result in creative solutions that reach more patients in the long run.

Another way to increase access is to reevaluate the role of primary-care physicians in the screening effort. Studies show the 96% of patients see their regular medical doctor on an annual basis. By offering screening on site during this initial appointment, through the use of telemedicine or Inoveon's DR-3DT™ service, we could significantly increase the number of patients being evaluated each year. Evidently, convenience is a major factor with regard to patient compliance for regular screening.

In addition to improving access through telemedicine and community-targeted programs, we should begin to explore the possibility of Internet-based care options. Although this may pose some challenges with regard to security and confidentiality, it is an area with a great deal of potential. Ideas range from creating a common platform for all major organizations involved in diabetes research and treatment, like JDRF, NEI, NIDDK, and HCFA, to the use of web-based diaries for patients who want to track and share information electronically with their physicians. The Staged Diabetes Managed Care Plan (developed through a Department of Defense contract) is one readily available program that offers a provider's task list, an online patient log, and the ability to create personal charts and graphs to monitor progress. For Internet-savvy patients, this may be the motivation they need to get involved in their own self-care.

Economic incentives play a major role in establishing a successful screening plan. We must look beyond doctor-patient interactions and consider other members of the health-care cast: insurers, employers, managed-care organizations, advocacy groups, and policy makers. Each group is motivated by its own set of incentives, and it is important to determine what factors are most influential in decision making and cost allocation. For insurers, surgery may seem expensive, but the money saved by detecting and treating retinopathy early is substantial. Likewise, for the patient, early screening and treatment can translate into eventual health care dollars saved. It may be difficult to precisely evaluate economic incentives and translate the findings into specific actions, but there is no doubt that changing financial and risk structures will bring the issue to the forefront in the near future.

Quality of Care

The panel recommended the following action items regarding quality of care:

- Simplify screening processes
- Obtain current patient data
- Develop comprehensive methods for record keeping
- Create systems to identify and eliminate errors of omission and commission
- Make eye exams a regular part of physical exams
- Improve awareness and communication regarding screening among the medical community, including primary-care physicians, internists, and diabetologists
- Explore the effectiveness of involving nurse care managers and practitioners more intensively in patient care and follow-up

Without a doubt, quality of care could be improved by simplifying the screening process. One suggestion is to develop an evaluation scale that could be read and implemented like other traditional "lab tests." A single-digit rating system that adhered to current standards would be valuable to the wider medical community. A more streamlined procedure might ensure that screening could be incorporated more easily into primary-care settings and would support increased application of telemedicine techniques as well.

In addition to simplifying screening, we also need to obtain more current data. Some of the studies on which we are basing today's decisions are 10 to 30 years old. Renewed efforts are needed to obtain up-to-date information, and we should explore options for generating new surveys. One idea is to enlist the endorsement and assistance of agencies like HCFA and NIH. We could also investigate the possibility of piggy-backing an evaluation component on an existing study, like the National Health Interview Survey. Much has changed in our prevention and treatment tactics over the years, and we need to find a way to accurately measure the results of such progress.

One way to ensure we have access to data that reflects current screening and treatment is to develop more effective and comprehensive record-keeping strategies. As of 2000, Medicare HMOs are required to report Health Plan Employer Data and Information Set (HEDIS) information based on the Diabetes Quality Improvement Project (DQIP). DQIP was developed to standardize the measurement of quality care for patients with diabetes and includes eye exams as one of its eight measures. It is hoped that this will reflect a more accurate picture of quality of care and screening than can be obtained by using either insurance claims or medical record reviews alone, which can result in an underestimation of the true rate.

Any plan for improving quality of care must include the increased ability to identify and eliminate errors. The fact that so many patients are treated for diabetes yet fail to get screened for retinopathy is a major red flag that signals a crack in the health care system. This is largely a systemic problem, but one that cannot be ignored. Other industries have built-in means for error detection and correction. It is time to consider new ways to prevent, or at least catch, a greater magnitude of medical errors. One idea is to merge medical management procedures with computer controls. Computer technology could also allow us to couple evidence-based medical knowledge with data to identify patients in need.

One way to prevent patients from slipping through the cracks is to make eye exams a regular part of routine physical examinations. Most patients don't get close to the minimum possible care for their diabetes or associated conditions, like retinopathy. It may be feasible to include screening in a comprehensive exam administered to diabetic patients to evaluate for glaucoma, cataracts, and retinopathy at the same time. By including retinopathy screening in the physical exam process, we could detect a variety of other medical problems as well. But most important, even after patients are evaluated, they still need to be integrated into a regular, consistent eye-care program that involves more than just screening.

While it may not be reasonable to expect primary-care physicians and internists to have the same skill detecting retinopathy as an ophthalmologist, it is important that they are aware of the value of regular eye screening and the availability of treatment. As a practical matter, it is important that a medical doctor be aware of the basics of ophthalmology, because many other conditions present in the eye area. Practitioners need to be able to competently examine the back of the eye and, more significantly, recognize the necessity of referring at-risk patients to a specialist. It is unlikely that primary-care doctors will emerge as frontline screeners in the fight against retinopathy, but their participation in the process would be an invaluable contribution.

To take this idea one step further, involving other members of the medical staff in screening efforts may also help to reach more people. Often a doctor's time can be limited or focused on more pressing medical issues. In these cases, it may be effective to have a nurse practitioner discuss screening with a patient and conduct follow-up reminders. There is an entire industry of diabetes management companies working hand in hand with managed care, and they have an excellent track record. However, this sort of system doesn't exist for patients enrolled in Medicare or other indemnity insurance companies. It would be worth investigating the more successful components of these programs and find ways to implement them on a broader scale.

Suggested Activities and Recommendations

The following specific action items emerged from the roundtable discussions:

1. Evaluate current public education programs with a diabetic retinopathy component to ensure that any follow-up projects do not duplicate existing programs. Evaluation can be enhanced through interviews with leaders of current programs (like NEI, NIDDK, JDRF, and ADA) to create a compendium of programs.
2. Review and coordinate a HCFA Medicare Diabetes Eye Exam program; for example, a pilot study proposal that could be implemented with its state Peer Review Organizations (PROs). This could help determine the effectiveness of similar programs in promoting eye exams and education if expanded for use as a model in other target areas. It could also garner data to measure any increase in the screening rate when resources are dedicated to improvement. And finally, it would help create a state-based PRO implementation toolbox that would help disseminate pilot study best practices.

3. Create a demonstration project with JDRF to further examine the use of telemedicine in retinopathy screenings.
4. Ascertain the current level of acceptance for and use of the standard diabetic retinopathy/macular edema progression rating scale with a long-term goal of simplifying the scale and promoting its use and understanding among screening providers.
5. Explore the possibility of converting the progression ratings scale into a single-digit, quantifiable “lab test,” along the line of a cholesterol test. This would maximize its usability throughout the medical community and make it applicable in a variety of situations, including ICD-9.

As a result of the workshop and roundtable forum, it has been possible to identify some “next steps” that will convert these strategies from ideas into action. Discussions are under way to develop more detailed plans for implementing some of the proposed projects, along with identifying available support staff to assist. Benchmark goals for each program will be determined, and timelines for development will be explored. In addition, JDRF will help to create a steering committee (comprised of key organizations) that will identify projects, leaders, objectives, and goals. Finally, we will draw advocacy groups into Working Group programs.

The following section provides an in-depth summary of all the workshop presentations and provides keen insight into how these recommendations and action items evolved.

Workshop Presentations

☒ Session I: Introduction to the Key Issues

The four presentations in Session I provide an introduction to the key issues addressed at this workshop. First, an overview of current practices in screening and eye exams for diabetic retinopathy is presented, followed by a briefing on patient population and patient-physician relationship issues. Next, various topics regarding cost effectiveness of screening practices are explored, followed by an overview of the role that new technology plays in enhancing patient access to eye care.

Current Practice in Screening and Eye Exams for Retinopathy: An Overview

T.W. Gardner, M.D., Pennsylvania State University

Diabetic retinopathy was recognized as early as 1855 to be a significant complication of diabetes. A hundred years later, patients were managing their conditions with diet alone, and doctors were investigating the benefits of photocoagulation for therapy and fundus photography as a means of diagnosis. In the 1980s, the first standards of care were developed, and today the prognosis for preserving vision is better than ever as a result of studies like the DRS, ETDRS, DRVS, and DCCT. Despite these advances, however, diabetic retinopathy continues to be a major health problem and remains the leading cause of vision impairment and blindness in the Western world in the twenty-first century.

There are several reasons for lack of more substantial progress in prevention and screening. One is inadequate communication between ophthalmologists and primary-care physicians regarding diagnosis and treatment. Another is the fact that patients who are asymptomatic do not seek screening that could detect diabetic retinopathy earlier. A third factor concerns available treatment options: Laser surgery is often the suggested course of treatment, but patients can be reluctant to follow through because of the possible pain and side effects. In addition, they commonly think that doctors have hidden incentives for recommending surgery, while insurance carriers balk at the procedure's expense. More significant, however, is the fact that laser surgery does not treat the underlying metabolic disorder.

It is clear that current methods of screening and treatment have proven inadequate, and most attempts to educate physicians and patients have not significantly improved screening rates or visual outcomes. Recent studies show that diabetes affects all retinal cells, including neurons, glial cells, and vascular cells, and future treatment must address this fact. Our conventional approaches will be further strained by the increasing diabetes epidemic over the coming decades. Current efforts should continue, but innovative means of diabetic retinopathy diagnosis and treatment must be developed with the underlying goal of preventing diabetic retinopathy altogether.

Patient Population and Patient-Physician Relationship Issues: An Overview

Emily Chew, M.D., National Eye Institute/National Institutes of Health

The current treatment of diabetic retinopathy with laser photocoagulation and vitrectomy has been proven to be highly beneficial in reducing the risk of severe vision loss. However, the number of patients who receive eye examinations still falls far short of the recommended guidelines of the American Academy of Ophthalmology and the American Diabetes Association. A number of factors contribute to the low eye-screening rates of patients with diabetes.

First, much can be learned by examining the population of persons with diabetes in order to identify reasons for decreased compliance with regular dilated eye exams. For example, the median age of patients with Type 2 diabetes is 64 years old. Approximately 72% live in urban areas, and many live alone. Only 21% have a college education. As such, many patients do not have adequate access to health education, social support, or even the necessary transportation to get to their medical appointments.

Second, patients with diabetes are plagued by a number of systemic complications that require more urgent medical care and may diminish the effects of impaired vision. Comorbidities include hypertension, renal disease, stroke, cardiovascular disease, and high cholesterol. It is not uncommon for patients to miss appointments with their eye care providers because of other pressing medical issues that result from these serious conditions.

Third, lack of patient-physician communication plays an important role in education and treatment. The importance of regular eye exams with an eye care provider needs to be stressed by the primary-care physician, internist, or diabetologist. Often, patients who have had their eyes evaluated as part of a physical examination in the medical doctor's offices will consider themselves to have had "eye exams." This is especially true when the physicians who performed the eye exams (usually through the undilated pupil) concluded that "the eyes look good." Important signs may be missed in such examinations. The medical physician should actively encourage or facilitate the patient's need for regular dilated eye exams with an eye care provider familiar with diabetic eye disease.

Other factors of the patient-physician relationship are more difficult to evaluate, such as the role fear plays in deterring patients from seeking care. It is clear that patient education and solid communication are fundamental to improved care and screening rates. Medical doctors need to be aware of successful treatment options and to stress the importance of dilated eye examinations to their patients. They should also emphasize the necessity of glucose, cholesterol, and blood pressure control and the benefits such management could induce. This approach, coupled with a focus on integration of care rather than organ-specific treatment, can help engender a sense of self-empowerment in patients that could result in improved screening and treatment rates.

Cost-Effectiveness Issues: Ending Blindness from Diabetic Eye Disease

Jonathan Javitt, M.D., M.P.H., Active Health Management

Few other cases in the health care arena are so self-evident with regard to cost savings and cost effectiveness as is the early detection of diabetic retinopathy. The argument for early screening and evaluation has been made and accepted worldwide, yet despite the overwhelming promise of successful treatment and savings, effective screening is implemented only about 50% of the time.

To determine cost effectiveness, a variety of cost analyses can be conducted to evaluate benefit, utility, and identification. Monetary benefits can be measured, as well as direct, indirect, and intangible benefits. Effectiveness can be viewed from different perspectives in terms of society, payers and providers, and patients. Ten years ago, limited data prevented us from determining the true cost effectiveness of early retinopathy screening, but with studies like the WESDR I-III, the DRS, the ETDRS, and others, we can affirmatively attest to its effectiveness.

A cost-effectiveness model was developed to measure how much vision was saved with early screening and at what cost. The model studied incidence, progression, evaluation and treatment, and mortality. With regard to societal cost, the model showed a federal government savings of \$1 billion, a personal cost of less than \$1,000 per patient, and a personal cost per quality of adjusted life years of less than \$2,000.

With regard to examination frequency, the model indicated that screening every two years should be adequate for patients with no known retinopathy. However, since patients are unpredictable about making and keeping such routine appointments, an annual recommendation for screening may get better results. Studies have shown that screening sensitivity is 80% or better when exams are done regularly. Incidentally, ophthalmoscopy and dilated photography seem to work equally well.

The next question is who should be doing the screening? Ophthalmologists have 70% to 90% sensitivity, and nonmydriatic photographs have 20% lower sensitivity than single-field dilated tests. Despite training, internists and family practitioners rarely show better than 40% sensitivity. Therefore, screening by eye care specialists and/or cameras is probably the most effective approach.

Eventually, single disease-focused screening will begin to hit diminishing returns. To find a permanent solution, we must investigate some of the underlying problems in the health care system. Foremost is the problem of medical error. Mistakes will occur; however, there is no built-in system for error detection and correction. One way to add checks and balances is to merge some aspects of disease management with computer controls. By coupling patient data with evidence-based medical knowledge, we can better identify patients in need and lower the rate of untreated patients.

Guidelines are available, but they are not always easy to implement. For example, doctors are required to see more patients than ever before, and a lack of time is cited as a frequent complaint. A computerized system might be of assistance. By applying computer technology to the problem, both doctors and patients could benefit. Some suggestions include Web-based tracking and assessment, as well as online patient diaries and logs.

There is global agreement that screening is cost effective. However, unless new approaches are developed for integrated disease management, this information remains purely academic. Our analyses show that total solutions would cost less than 3% of total health care costs, yet we still fail to get the screening done. The problem lies not in the ophthalmology community but with systemic faults in the medical health care process.

Role of New Technology in Enhancing Patient Access to Eye Exams

Sven-Erik Bursell, Ph.D., Beetham Eye Institute, Joslin Diabetes Center

Many studies have demonstrated the value of accessing diabetic patients into a program of eye care, including an annual eye examination. The value associated with regular eye care is evident in the significant savings that are accrued, both in vision and economy. Despite these findings,

however, other studies indicate that only 50% of all diabetic patients are currently accessed into appropriate eye-care programs. One approach to solving this problem may be the increased use of telemedicine technology.

Telemedicine provides an accessible vehicle for performing eye imaging at the point of care, eliminating the need for a separate screening appointment. Images are captured and transmitted to a central resource for accurate assessment. The current technologies available to facilitate this process are primarily associated with the acquisition of digital images of the retina using either mydriatic or non-mydriatic retinal fundus cameras. These digital images can then be distributed over industry-standard telecommunication systems to centralized reading centers. Here the level of diabetic retinopathy can be evaluated, and the results of the assessment can be transferred back to the provider at the point of care.

The technologies used in telemedicine are rapidly emerging and are becoming more cost effective. They include higher resolution and lower light-sensitive digital cameras, higher bandwidth availability over the Internet, and the development of expert systems designed to automate retinal lesion detection for diagnosing the level of retinopathy. They also include the integration of visible light objects into existing and commercially available Picture Archiving Computer Systems (PACS) environments that have traditionally dealt exclusively with radiology images. In parallel with these emerging technologies is a developing set of standards used to facilitate data interchanges in this environment, including DICOM, Health Language (HL7), and HIPPA security standards.

When telemedicine is used in the clinical environment, we find that patient access into an eye-evaluation program is improved, as is the process of appropriate ophthalmologic referral. Additionally, we find that the patient's ability to review their own retinal images on the computer monitor with their care provider provides an effective education tool and appears to empower the patient with respect to improving personal diabetes management.

Emerging technologies like telemedicine can provide significant benefits for providing increased access of diabetic patients into appropriate eye care programs. However, as with all new technology, the application must continue to be clinically and technologically validated before its widespread adoption in the clinical care arena.

Session II: Patient Population and Patient-Physician Relationships

In Session II, seven case studies are presented exploring a variety of issues related to patient populations and the patient-physician relationship, particularly as it affects access and quality of care. An overview of different perspectives on care is given, along with a description of different demographic features used in one study to predict compliance with recommendations for annual eye examinations. Specific focus is given to African American, American Indian, Native Hawaiian, and inner-city populations. Finally, a best-case scenario is presented detailing a hypothetical patient's optimal clinical management to prevent progression of retinopathy.

Perspectives on Care

Paul Lee, M.D., J.D., Duke University

Research shows that 90% of vision loss is preventable, but compliance with recommended evaluation and treatment is less than 60%. With many patients not using appropriate eye care, it is

imperative to determine why they do not get treatment and continue to suffer preventable vision loss from diabetic retinopathy.

One way to get a clear perspective on the problem is to discuss the issues with the patients directly. Our study used structured interviews and focus groups comprised of four types of individuals: (1) patients with diabetes for at least 5 years who have suffered vision loss in at least one eye (20/200) due to diabetic retinopathy; (2) patients with diabetes who have had at least background retinopathy but have preserved vision in both eyes (20/40 or better); (3) family members of those with diabetes; and (4) the range of care providers for patients with diabetes. The sessions were taped and transcribed, and content analyses were then performed in an attempt to find some answers.

Three major themes emerged from the content analysis. First, there is significant variation and room for improvement in the quality of health care provided to patients with diabetes that has a direct bearing on how well patients fare. Levels of patient education vary significantly, and more individual focus is needed rather than a "one size fits all" approach to every patient. A related problem centers on the frequent lack of trust between doctors and patients. Second, patient interventions can be evaluated only in a targeted, "niche-like" analysis; it is unrealistic to expect any intervention program to positively affect more than a small portion of patients with diabetes. This applies particularly to increased use of eye care services among patients already seeing primary-care physicians and endocrinologists. Third, family involvement is not always uniformly positive. Social-related issues that revolve around cultural practices and gender roles in families must be taken into consideration. Assessment and matching of the dynamics of the patient-family relationship are critical, particularly in motivating patients to conform to recommended, periodic follow-up care.

Even for patients who use health care, significant challenges exist with regard to obtaining eye exams and, more important, to obtaining appropriate continuing eye care. Doctors need to be aware that patient trust and confidence play a significant role in successful health care. In addition, they must be certain to communicate risks and reassurances clearly in order to keep patients informed and involved in their own health management. Without these efforts, even patients who have regular diabetes care and even diabetes-related eye care are at risk for preventable vision loss.

Eye Exams and Their Relationship to the Progression of Microvascular Complications in a Cohort of African Americans with Type 1 Diabetes

Monique S. Roy, M.D., UMDNJ-New Jersey Medical School, Department of Ophthalmology

The "New Jersey 725" is a well-characterized group of African Americans with Type 1 diabetes identified for this study from the New Jersey Hospital Discharge data for 1982–1996. Patients had been admitted to one of the 31 New Jersey hospitals located within a 20-mile radius of the New Jersey Medical School in Newark where the study was conducted. Inclusion criteria were Type 1 insulin-dependent diabetes diagnosed before 30 years of age and current insulin therapy. For the purpose of this study, three bilaterally blind patients were excluded, leaving a total of 722 patients.

The mean age of patients was 28.5 years, and there were slightly more women (58.3%) in the study than men. Forty-three percent of the group was middle class, and slightly more than half was lower class. The clinical examination included a detailed eye examination, seven field fundus

photographs, and blood pressure measurements. The biological evaluation included blood-glycosylated hemoglobin values and kidney functions.

About a third of the group had never been examined by an ophthalmologist, although 79% had been told to have their eyes examined. Of those who had seen an ophthalmologist, only 52% were in the care of a regular ophthalmologist. A majority (59.7%) attended an eye clinic, and 40.3% had a private ophthalmologist. Only 51% saw their ophthalmologist once a year or more.

As part of a structured interview, patients were asked about eye care and health insurance coverage. With regard to insurance, 71.8% had eye care coverage—most frequently Medicaid only or HMO only. With regard to eye care, 41.6% had had a dilated eye examination within the past 12 months, and 29.6% had never had one. Most (78.5%) patients had had a dilated examination performed by an ophthalmologist and only a minority (17.1%) by an optometrist. Having a dilated eye examination in the previous 12 months was significantly and independently associated with higher socioeconomic status, not working, and having either private or clinic-based eye care.

The data suggest that a large portion of African Americans with Type 1 diabetes do not receive recommended eye care to detect diabetic retinopathy and prevent visual impairment and blindness. Based on interviews and exam rates, it is clear that simply telling patients to get screening is not enough. More than three-quarters of the group had some form of health insurance, and many were encouraged by their family physicians to get regular eye examinations. Some of the patients interviewed said that they didn't follow up with eye exams because they weren't experiencing any symptoms. Others reported transportation or child-care problems as the reason for their lack of follow-up, as well as preoccupation with other more serious or debilitating health problems.

These findings suggest a need for simple, culturally sensitive public health education that is disseminated repeatedly in a community-based environment. In addition, the importance of bringing accessible screening opportunities into the community cannot be denied.

Patient-Physician Relationships in the Diabetic American Indian Population

Kelly Acton, M.D., M.P.H., Indian Health Service

The concepts of family and community are as important to Native Americans as the concept of individual self is to a member of Western culture. Unfortunately, many of these fundamental values create barriers to communication and care when the two cultures are brought together in a health care setting.

Some of the patient barriers that exist relate to different concepts of illness. Some native Americans do not understand the etiology of disease and may attribute sickness to ill will, spirits, or punishment. They also have little experience with chronic disease, especially one that is "silent" like diabetes and causes no pain or outward symptoms. They tend to rely on traditional healing systems, which can be positive when used in concert with conventional treatment but may not be so effective when used alone. In addition, various cultural attitudes may deter an individual from seeking treatment. For instance, a person with a stoic demeanor is more highly regarded than someone who reacts emotionally and asks for "unnecessary" attention. Unfortunately, this type of behavior can have devastating health consequences.

Lifestyle issues also come into play. A lack of physical activity and the negative effects of acculturation, such as alcoholism, only contribute to health problems. Obesity is also common, perhaps the result of a culture who used to eat according to the available and variable food supply

but who now has stable and steady access to food. In addition, in certain social situations within this community, under-eating can be construed as an insult.

Other problems include translation difficulties and behavioral differences between medical doctors and Native Americans. For instance, in a culture that reveres the wisdom of its elders, Western doctors may seem too young and direct for most Native Americans. In addition, they talk about concepts like the future and death, which makes their patients uncomfortable to the point of avoiding care altogether.

In order to more effectively screen and treat the Native American population, a stronger focus is needed on communication issues to resolve some of the existing barriers. Providers need to take time for cross-cultural orientation, learn to focus on one-concept teaching methods, and avoid scare tactics when dealing with patients. Approaches using visual teaching and learning may produce greater compliance than those requiring individuals to do extensive writing and record keeping. Finally, psychosocial issues must be addressed since they have such significant impacts on the health management skills of this population.

Patient-Physician Relationships in a Diabetic Native Hawaiian Population

Marjorie K. Mau, M.D., M.S., University of Hawai'i

Diabetes is a major health problem that was first reported in 1958 to disproportionately affect Native Hawaiians at a prevalence rate two times higher than all other ethnic groups in Hawai'i. Since 1960, diabetes mortality rates among Native Hawaiians have also exceeded rates in all other ethnic groups in the state. Today, the health burden of diabetes has reached epidemic proportions. However, because the major source of morbidity and mortality in persons with diabetes is due to the associated micro- and macrovascular complications rather than diabetes itself, improvements in diabetes health outcomes should focus not only on intensive glycemic control but also on the prevention and prompt treatment of associated complications.

Although efficacious therapies to prevent and/or postpone long-term complications are well known, significant challenges remain in translating these landmark findings into clinical practice, especially among high-risk minority populations such as Native Hawaiians.

Previous studies on the patient-physician relationship have shown that medical compliance and patient satisfaction are associated with a positive patient-physician interaction. In order to capitalize on these findings, it may be necessary for physicians treating Native Hawaiians to alter their communication style with patients to take into account various cultural and social considerations.

Such a model for enhancing patient-physician communication has been developed elsewhere as part of a medical education curriculum. Based on our clinical and research experience working with Native Hawaiian communities, we believe this model has potential as a framework for enhancing diabetes care in Native Hawaiian communities. Recognizing the importance of physicians in effective diabetes programs for Native Hawaiians, this cross-cultural approach to patient care has the potential for broader application for other illnesses that disproportionately affect Native Hawaiians and other ethnic minority populations.

Finally, improving patient access to screening in remote areas through the use of telemedicine technology and developing more community-based programs would be two effective steps toward better eye care options for the growing Native Hawaiian diabetic population.

Approaches to Diabetic Retinopathy Screening and Prevention in Inner-City Populations

Robert N. Frank, M.D., Kresge Eye Institute; Wayne State University School of Medicine

Retinopathy screening was conducted through a program sponsored by the Michigan chapter of the American Diabetes Association (ADA) to study evaluation and follow-up exams in inner-city populations. Twenty-six screening centers were established throughout the state, and publicity describing the free screening was distributed in public locations, most notably in stores, community centers, and churches. Of the 338 patients screened, 20 were found to have vision-threatening retinopathy, 46 had serious retinopathy, and 29 showed signs of mild retinopathy. In our screening center, which was staffed by ADA personnel, a senior ophthalmologist, and an ophthalmology resident, 18 subjects underwent complete eye examinations and were counseled regarding follow-up and treatment.

Our prevention approach is based on a program initiated by the Wayne State University Department of Community Medicine involving intensive diabetes education for diabetic subjects and their families, which took place in churches serving the African-American community in Detroit. We plan to explore whether such intensive education programs, coupled with close medical follow-up, can reduce risk factors for complications of diabetes, including retinopathy, in subjects with Type 2 diabetes in this population.

The study is a randomized, controlled clinical trial of intensive education compared to "standard" diabetes follow-up in a total population of 400 subjects over a 3-year period. In addition to retinopathy screening, we will assess the following risk factors: fasting and random blood glucose, glycated hemoglobin, blood pressure, body mass index, and serum lipids (total cholesterol, HDL-cholesterol, and LDL-cholesterol).

Only the initial series of examinations in the screening protocol has been completed. Phone calls were made and letters were sent to ensure that these individuals sought immediate treatment and follow-up. Despite these efforts, the program has a 25% dropout rate. It is clear that much wider publicity is necessary to attract more subjects, in particular those who have until now been outside the network of health care providers. (Many of the subjects who attended our center were already being followed by other eye care professionals and came to the screening simply to get "second opinions.") These patients will often require referrals, not only for ophthalmic care, but also for care of other aspects of their diabetes and its complications. In addition, the use of new approaches to screening, like the use of telemedicine technology, may have a positive effect.

The proposed controlled clinical trial in our prevention program has not yet begun, but pilot results from the Department of Community Medicine suggest that intensive education and follow-up in this population can be as effective in reducing risk factors for complications and, ultimately, the complications themselves, as was the case in the Diabetes Control and Complications Trial for Type 1 diabetes and the UK Prospective Diabetes Study for Type 2 diabetes in different groups.

Demographic Features Predicting Compliance with Recommendations for Annual Retinal Examination

E. B. Feinberg, M.D., M.P.H., Boston University School of Medicine and Boston Medical Center

In an effort to understand why so many diabetic patients neglect to obtain regular eye care, a study was conducted to investigate whether various patient characteristics can predict compliance with recommendations for annual dilated retinal examinations.

We performed a cross-sectional analysis of 188 patients who agreed to participate in a follow-up study of nutrition and diabetic outcomes. Multiple patient characteristics were recorded and analyzed as risk factors for compliance with retinal examination guidelines, including age, gender, race-ethnicity, marital status, literacy, spoken and written language ability, education level, insurance status, primary-care provider race, language, gender concordance, diabetes type, diabetes duration, treatment method, and recent Hgb A_{1c}. For each characteristic, an odds ratio for compliance was calculated using univariate and multivariate logistic regression methodology.

Our results indicate that race, gender, age, language ability, education level, and insurance status do not necessarily predict compliance with guidelines for dilated retinal examination. Of the patient characteristics studied, only Type 1 status predicted compliance, with an odds ratio of 11.72 ($p = 0.0338$).

Although the outcome of this study may be unique as a result of the study environment, it seems clear that efforts to increase compliance could increase effectiveness by targeting Type 2 patients.

A Best-Case Scenario: A Hypothetical Patient's Optimal Clinical Management to Prevent Progression of Retinopathy

Ronald Klein, M.D., M.P.H., Department of Ophthalmology and Visual Sciences, University of Wisconsin

The following scenario illustrates an evidence-based approach for the medical management of an individual with Type 2 diabetes and minimal diabetic retinopathy. A 52-year-old woman with a 4½-year history of Type 2 diabetes treated with metformin and diet is referred to an ophthalmologist with a chief complaint of slightly blurred vision. She is overweight, has a history of "labile" hypertension, has high cholesterol treated with diet, and is post-menopausal. She smokes five to seven cigarettes per day. Her father had a history of hypertension and a stroke and her mother had open-angle glaucoma. Her glycosylated hemoglobin A_{1c} have run between 8.5% to 9%, her blood pressure ranges between 140/86 to 166/90 mmHg, her LDL-cholesterol ranges between 140 to 180 mg/dL, and microalbuminuria is said to be present. Undilated ophthalmoscopy by her internist is normal. The examination reveals a blood pressure of 148/90 mmHg, best-corrected visual acuity of 20/25 in each eye, early cataracts, and slightly elevated intraocular pressures of 22 mmHg in each eye. Funduscopy reveals a few microaneurysms in each eye.

We advise her that lowering her cholesterol will lower the risk of cardiovascular disease and may be of benefit in lowering the risk of developing lipid deposits in the retina. We also tell her that the cataracts are probably causing a decrease in vision. Lowering blood sugar is be of benefit in reducing risk of progression as well. The risk of glaucoma is higher in persons with a family history of glaucoma, and because the pressure in her eyes is elevated, it needs to be checked along with the optic nerve on a regular basis. Smoking, while not a cause of diabetic retinopathy,

is associated with decreased life expectancy and should be stopped if possible. Yearly dilated eye examinations are indicated for cataract and glaucoma, as well as to make sure that vision-threatening retinopathy has not developed. If the latter has developed, photocoagulation may be of benefit in reducing loss of vision due to the retinopathy.

Ideally, in a best-case scenario, a well-directed patient-physician dialogue will lead to a clearer understanding of the patient's lifestyle, concerns, and beliefs, which may help in her health management. In this case, the patient enjoyed reading as a hobby, so her vision was of special concern, but she also believed that Type 2 diabetes was not "as bad" as Type 1. It may also be useful for the physician to follow up with a letter or take other actions to establish a relationship that promotes trust and understanding rather than fear and confusion.

Session III: Cost-Effectiveness Issues

In Session III, three case studies are presented examining cost-effectiveness issues as they relate to retinopathy screening. In the first study, findings from a local practice improvement project are reported. The second study addresses the usefulness of economic health information when it comes to informing public health policy and decision making. The last study explores a public-private partnership developed to increase screening rates among Medicare beneficiaries.

Eye Exams for Diabetic Retinopathy as a Performance Measure of Quality: Findings from a Local Practice Improvement Project

John Oh, M.D., M.P.H., KePRO, Inc., Harrisburg, PA

State-based Medicare peer review organizations (PROs) are under federal contract with the Health Care Financing Administration (HCFA) to improve the quality of care for Medicare beneficiaries. In the current Sixth Scope of Work contract (1999–2002), diabetes is one of six clinical priorities for national quality improvement. Consequently, the PROs are working with physicians, Medicare beneficiaries, and community organizations to improve diabetes care for patients. Based on 1997–1998 Pennsylvania Medicare fee-for-service claims, 70% of Medicare beneficiaries aged 75 and younger had evidence of an eye exam in the past 24 months, higher than previously estimated.

The Diabetes Quality Improvement Project (DQIP) was developed to standardize the measurement of diabetes care quality. DQIP applies to persons with diabetes who are aged 18 to 75 years and includes quality indicators measuring eye exams, glycemic testing and control, lipid testing and control, foot exams, assessment of nephropathy, and blood pressure control. For DQIP, the eye exam indicator gives credit for an eye exam performed in the past year, or in the past 2 years for "low-risk" persons. "Low risk" is defined as not being on insulin, a most recent HbA_{1c} of less than 8.0%, and a normal eye exam in the year before the reporting year, although there is some uncertainty regarding the proper screening interval.

Beginning in 2000, the Health Plan Employer Data and Information Set (HEDIS) has used the DQIP quality indicators in its Comprehensive Diabetes Care set of measures. Each of the Medicare+Choice organizations (Medicare HMOs) is required to report HEDIS. Health plans use a combination of administrative claims and medical record reviews to capture all the eye exams received by members with diabetes. It is worth noting that using either claims or medical record reviews alone results in underestimation of the true rate.

KePRO recently recruited 45 primary-care practices in Pennsylvania to participate in a diabetes practice improvement effort. Nurses were sent into the practices to provide assistance, and we tried to enlist the support of medical leadership in our recruitment efforts. We reviewed the medical records of 4,531 patients with diabetes and ranked the practices. We found that the aggregate eye exam rate was only 41%, although we did not have access to insurance claims to determine if there were eye exams not captured through medical record review. In discussions, many physicians expressed concern that eye care professionals do not routinely communicate the results of eye exams performed on their patients with diabetes. They noted that there were often competing medical problems that demanded more immediate attention, and they listed documentation problems and insufficient staff as other barriers to follow-up. KePRO is presently working with the state eye care professional organizations to improve communication. In addition, we are strongly encouraging primary-care physicians to adopt simple flow sheets, implement reminders and recalls, delegate office staff, and employ other proven interventions that have demonstrated effectiveness in raising eye exam rates.

Using Health Economic Information to Inform Health Policy and Decisions

Erik J. Dasbach, Merck Research Laboratories

Information from economic evaluations can be useful for determining whether or not a new health care program (for example, a new strategy for screening for diabetic retinopathy) is worthwhile and should be adopted. The market for economic evaluation information includes public and private payers, policy makers, physicians, and patients. In the United States, the target audience specifically includes managed care organizations, health insurers, employers, advocacy/professional groups, and advisory groups. The information from evaluations can be employed in a variety of ways, such as recommending cost-effective health programs, developing drug and vaccine formularies, and supplementing guideline recommendations.

To this end, numerous economic evaluations of health care programs are available in the scientific literature. In terms of diabetes health programs, a variety of economic evaluations have been published demonstrating that screening for diabetic retinopathy represents a worthwhile investment of health care dollars. Despite such favorable messages, however, the use of economic evaluations to inform actual decisions about adopting new health care programs in the United States is neither well defined nor routine.

Hence, given that the goal of this workshop is to develop strategies for recommendation to the health services community, it is not clear in the United States what their economic information needs are. In the absence of such guidance, it may be instructive to examine what some of the common barriers are to the acceptance and use of economic evaluations by decision-makers. Common barriers include the generalizability of the costs, measures of effectiveness, time horizon, and comparators incorporated into the economic evaluation. Two possible approaches may help to overcome these barriers: (1) the development of general computer models that allow users to customize economic analyses to the decision-maker's current practices, and (2) partnering with decision makers to design "real world" studies in their setting. In order to increase the likelihood of acceptance and use of economic evaluations, we need to identify the specific decision makers who will use the analyses, learn what these decision makers need in terms of economic information, and tailor the health programs and analyses to meet these needs.

A Public-Private Partnership to Increase Eye Exam Rates for Medicare Beneficiaries with Diabetes

Barbara Fleming, M.D., Ph.D., Health Care Financing Administration

The Health Care Financing Administration (HCFA) selected diabetes as a 6-year focus for measurement and quality improvement in the Medicare program. Improving rates of eye exams has been a major area of interest. Baseline data on eye exam rates were collected for 305 Medicare managed-care plans and for 2 million beneficiaries in the fee-for-service program. The biennial eye exam rate for the 2 million beneficiaries between the ages of 18 and 75 was 69%. Clearly, room for improvement exists.

In order to guide efforts to improve these rates, HCFA conducted a literature search of other efforts to improve care in this area. Two barriers to care appeared: the co-pay and lack of transportation. To reduce these barriers to care, HCFA joined forces with the American Academy of Ophthalmology (AAO) and the American Optometric Association (AOA).

Each organization brought key resources to the table. HCFA offered an ability to identify Medicare beneficiaries who had not had eye exams and had the authority to do mailings to those individuals. AAO had a National Eye Care Program that provided beneficiaries who had not had an eye exam in 3 years access to ophthalmologists who could provide care at no cost to the beneficiary. AOA offered options for reviewing the beneficiaries' financial circumstances and waiving the co-pay on a case-by-case basis.

The three groups launched a major national initiative that included direct mailings to all eligible beneficiaries and distribution of television, radio, and print public service announcements. Articles were placed in high-profile magazines (such as *Parade* and *Modern Maturity*) to target eligible beneficiaries. A paid ad was placed in the *National Medical Association Journal* for 2 months. Medicare carriers have, in some states, sent mailers to all physicians to alert them to the program. Individual peer review organizations in each state have added to these national efforts, to greater or lesser degrees. It should be noted that call rates were significantly higher following the *Parade* article than the rates generated by mailings.

Interim results, based on hotline phone statistics, show a 4% call rate (with a range of 2% to 15% by state). The true impact of these efforts will be determined by early 2001, after a review of the Medicare claims data. The first year of this effort will allow evaluation of impact by state and by intervention. For example, call rates dwarfed the impact of mailings after articles appeared in *Parade* magazine. It is expected that efforts in subsequent years can be carefully targeted to produce maximum impact. This partnership leverages the resources of each group to achieve the common goal of increasing rates of eye exams in the Medicare population with diabetes.

Keynote Presentation

Improving the Care of Patients with Diabetes

Frederick Ferris, M.D., National Eye Institute

Diabetic retinopathy is the leading cause of blindness in young adults, ages 20 to 55. Over the last two decades, the National Eye Institute has supported five landmark multi-center randomized clinical trials for diabetic retinopathy. These major trials were the Diabetes Control and Complications Trial (DCCT), the UK Prospective Diabetes Study (Type 2) (UKPDS), the

Diabetic Retinopathy Study (DRS), the Diabetic Retinopathy Vitrectomy Study (DRVS), and the Early Treatment Retinopathy Study (ETDRS).

The recommendations from these trials can be summarized as follows. Tight control of glucose, blood pressure, and serum lipids is effective in preventing complications from retinopathy. Scatter treatment should be deferred for eyes with mild or moderate non-proliferative diabetic retinopathy. As the retinopathy progresses to the severe non-proliferative or early proliferative stage, scatter treatment should be considered, especially in older patients. Scatter photocoagulation should be performed for virtually all eyes with high-risk proliferative retinopathy. Eyes with clinically significant macular edema should be considered for focal coagulation. Finally, early vitrectomy should be considered for advanced active proliferative diabetic retinopathy, and, most important, all patients with diabetic retinopathy should receive careful follow-up.

Before the advent of these treatments, the diagnosis of proliferative diabetic retinopathy carried with it a prognosis of blindness within 5 years for more than 50% of the patients. Patients in the ETDRS were treated with current recommendations for photocoagulation and vitrectomy. Blindness rates from this study show how implementation of the recommendations from the diabetic retinopathy clinical trials in patients with proliferative diabetic retinopathy can significantly reduce the risk of blindness. By implementing the ETDRS treatment recommendations, the risk for patients is reduced to less than 5% for legal blindness and to only 1% for severe visual loss. Thus, appropriate screening and treatment can yield more than a 90% reduction in blindness as a result of retinopathy.

In the course of daily practice, it is important for doctors to realize that diabetic retinopathy can be successfully managed, and patients can remain well for the long term with normal, routine follow-up. Based on study findings, the keys to successfully preventing blindness are regular screening, careful follow-up, and timely treatment.

Session IV: Role of New Technology in Enhancing Patient Access to Eye Exams

In Session IV, three case studies are presented exploring the role new technology plays in enhancing patient access to retinopathy screening and evaluation. The first study takes a unique look at the implementation of telemedicine evaluation in a Texas prison setting. The second study describes a new telemedical evaluation service designed to access patients in the primary-care setting, and the third looks at telemedicine screening programs in the American Indian community in California.

Implementation of Telemedicine Evaluation of Diabetic Retinopathy in a Prison Setting

Helen K. Li, M.D., University of Texas Medical Branch

Telemedicine evaluation of diabetic retinopathy is seen by many as an ideal application for remote eye care delivery in a variety of patient populations. However, this approach presents many implementation challenges. There is fear that the physical separation between patient and physician will weaken traditional patient-provider relationships. The opportunities and barriers

presented by telemedicine may be as important in determining its widespread acceptance and use as are considerations of cost and efficacy.

This case study reports on lessons learned from integrating teleophthalmology diabetic eye disease management between tertiary-care center University of Texas Medical Branch in Galveston and the Texas Department of Criminal Justice regional medical facility. It describes the preferences and attitudes of 200 diabetic inmates and their health care providers toward telemedicine evaluation.

The similarities between the inmate study group and the free diabetic population include low socioeconomic class, a disproportionately African-American and Hispanic representation, unmet medical needs, poor general health, and use of managed care. Differences include a more transient population and special barriers such as security and transportation issues.

The study's two-part survey revealed that although normal anxiety regarding evaluation and diagnosis still exists, patients were very impressed with telemedicine and liked seeing their own eye imaging. They also appreciated the ease of access that telemedicine afforded them, as well as the physical comfort resulting from the absence of dilation. Most reported that they didn't mind the delay between screening and diagnosis. Telemedicine afforded these patients easier access to diabetic eye specialists and allowed them to become partners in the prevention of diabetic complications with regard to their own health.

The study found that the impact of telemedicine on primary-care providers and ophthalmologists includes an increased need for information technology knowledge and access to diagnostic support. Eye care providers will also experience a possible increase in efficiency, a larger patient population in an expanded geographical range, and a decrease in direct patient contact. Both groups will experience an increased need for a coordinated flow of information between care providers.

We also learned that operators need a general understanding of diabetes and good patient communication skills, as well as solid technology training and excellent camera skills. With regard to imaging, we learned that image quality is operator-dependant as well as patient- and eye-dependant. Therefore, additional guidelines for optimizing image quality must be established.

Value=Quality/Cost: The Value of Telemedical Diabetic Retinopathy Evaluation

Stephen Fransen, M.D., Chief Scientific Officer, Inoveon Corporation; Associate Professor of Ophthalmology, University of Oklahoma Health Sciences Center

In an effort to provide high-quality, scalable, accessible eye screening to the increasing population of patients at risk for diabetic retinopathy, Inoveon has introduced Diabetic Retinopathy-3DT™ service (DR-3DT™). DR-3DT™ provides efficient, turnkey retinopathy evaluations in the primary-care setting. Because 96% of patients see their primary-care physician on an annual basis, there is a greater chance of improving screening rates by encountering patients in this environment. By involving the primary physician at this early stage, there is increased opportunity for patient education and improved patient-physician communication.

During the evaluation, demographic and basic health data are collected, and the patients' eyes are dilated. Subsequently, the seven standard fields, defined by the Diabetic Retinopathy Study (DRS), are imaged stereoscopically using a digital fundus camera. Intraocular pressure is measured at the end of the evaluation.

Images are transmitted via the Internet to Inoveon's Evaluation Center, where non-physician experts grade specific lesions of diabetic retinopathy. Their findings are returned to a central server-based algorithm that generates an Early Treatment Diabetic Retinopathy Study (ETDRS) Final Retinopathy Severity Scale Level and Macular Edema status for each eye, along with a recommendation based on the Preferred Practice Pattern™ for Diabetic Retinopathy of the American Academy of Ophthalmology. The normal turnaround time for evaluation is approximately 48 hours, at which point a recommendation is sent to the primary-care physician who ordered the evaluation.

DR-3DT™ is built on the gold standard for the evaluation of diabetic retinopathy established by the DRS and ETDRS. Prior to deployment for clinical care, the system was validated against this standard. In operation, an intrinsic quality assurance process randomly returns images to the Evaluation Center for repeat grading. These "over-reads," when compared with the primary grading performed on the same images, form the basis for ongoing DR-3DT™ quality assurance.

Based on our experience with the DR-3DT™, we recommend that new methods for diabetic retinopathy evaluation should focus on the primary-care environment, be designed to scale, implement established standards, and monitor quality assurance.

Telemedicine-Based Diabetic Retinopathy in the American-Indian Community in California

Heather Bernikoff, California Telehealth and Telemedicine Center

In 1998, according to information from the Centers for Disease Control and Prevention, 9% of American Indians suffer from diabetes, and members of this community are nearly three times more likely to be diabetic than non-Hispanic whites. In California alone, there are over 103 federally recognized American Indian tribes and 43 non-recognized tribes. Yet despite their high-risk rate, California American Indians face significant geographic, socioeconomic, and cultural barriers to accessing specialty medical service.

Through our grant program, the California Telehealth & Telemedicine Center (CTTC) is promoting the installation of telemedicine equipment to screen for diabetic retinopathy and is providing additional funding for staff training in California's Indian Health Programs. The goal of the program is to double the currently low retinopathy screening rates among California American Indian diabetics, which lag behind the national average for American Indians by 7%. CTTC has partnered in this initiative with the California Rural Indian Health Board, the Los Angeles Eye Institute, Dennis Rose and Associates, and the California Indian Health Service.

The program's objectives are to increase the number of California American Indian diabetics receiving annual eye exams by 100% and reduce the prevalence of diabetes-related blindness and vision impairment. It will also seek to increase the capacity of the California Indian Health Programs to conduct exams through the use of advanced technology and training for retinopathy screening services. Finally, it will establish a foundation for the appropriate expansion of telecommunication-based health care. CTTC outreach efforts to support these goals have included conferences and presentations; flyers, press releases, and reminder phone calls; articles in American Indian periodicals; and "word of mouth" via their Advisory Committee and others.

A variety of activities are scheduled for 2001. Equipment will be deployed to health centers, where on-site refresher training will be offered. Ongoing technical support will be available, and quality control checks of images will be performed. In June, a request for proposals will be released, offering eight additional Indian Health Programs the opportunity to be funded for

teleophthalmology. As these endeavors proceed, program members will continue to build on established keys to success, such as the inclusion of members of the target community in the project, comprehensive planning, especially through the use of a projected timeline, detailed research, and constant communication—keeping program partners well informed.

Telemedicine applications, when used in the primary-care setting, can not only address access issues in terms of geography, but can traverse barriers created by cultural differences that can prevent access to specialty services for the California American Indian community. Potential cost savings, when telemedicine-based ophthalmology care is used as a triage tool, can ameliorate socioeconomic barriers faced by the patient as well as the primary-care site.

In addition, insurance payors such as Medi-Cal (Medicaid) can facilitate the use of such technology in California by allowing reimbursement for this type of store-and-forward telemedicine-based clinical care.

Session V: Summary

In Session V, 10-minute summaries from each session moderator are presented. For specific recommendations and actions items that emerged from these sessions, see section IV of this proceedings report, Findings and Recommendations.

Session I

Jinan Saaddine, M.D., M.P.H., Centers for Disease Control and Prevention

Diabetes is a costly public health problem that is only expected to increase in the future. One complication of diabetes, diabetic retinopathy, is the leading cause of blindness in working-age people today. Despite that fact that treatment is available, people continue to suffer vision loss because they don't get regular eye screening.

Studies have shown that screening is cost effective and can prevent the progression of retinopathy because it allows for early treatment. Successful screening methods exist, including ophthalmological examination, retinal photography (fundus cameras, telemedicine, etc.), or a combination of the two. Whatever method is used, 80% sensitivity rates or better are preferable.

With regard to increased use of new technology, it is clear that methods like telemedicine improve access and empower patients to become involved in their own care, but such technology still needs more testing and validation.

Strong patient barriers exist that tend to inhibit improved screening rates, including lack of patient education, transportation problems, trust and cultural issues, social disintegration, and the burden of dealing with other, more pressing medical and appointments. On the provider end, barriers include lack of communication and plans for culturally aware diabetes education. The health care system needs to provide more access to screening in remote areas, incorporate screening as part of regular physical examinations, and evaluate new financial structure considerations. Changes in patient and physician behavior, as well as in the health care system at large, may effect positive results, but this would be difficult to accomplish.

Some realistic suggestions for improving screening include reminders and recalls, patient profiling, increased interaction between eye specialists and primary-care physicians, and a simplification of the evaluation process. The problem must be viewed from a population perspective and not just on a clinical trial basis.

Session II

Dan Stryer, M.D., AHRQ

Retinopathy screening rates are unacceptably low. In part, this is due to the fact that so many patients lack adequate medical insurance. But in many cases, patients are not being screened despite coverage. Sometimes, a co-pay prevents patients from accessing screening. In other instances, primary-care physicians are not giving referrals because they lack knowledge about the benefits of early detection and treatment or because a well-defined pathway for patient referral is lacking.

All too often, time is limited and doctors have to address other, more pressing health issues. This scenario leads to problems with patient-provider interaction. Doctors struggle to assess the patient, uncover potential barriers that might exist in the patient's environment and social support structure, devise a culturally sensitive approach to care, and engender trust—all in 7 minutes (the typical time some HMOs have allotted for doctor-patient interactions)!

The best way to improve screening rates is to make screening more accessible to the patients. They must be taught that screening is a priority for their health care, and providers need to understand how issues of trust, communication, and values can help or hinder their efforts.

In addition, we need to build partnerships with communities, which can take time and patience. Also, providers should focus on developing foolproof systems that will prevent patients from falling through the cracks. Finally, as we look to the future, we must acknowledge that new developments in genomics may play a part in future screening strategies. As we gain a better understanding of whom is at risk, we can translate this theoretical information into action.

Session III

Richard Eastman, M.D., Cygnus, Inc.

It is a fact that eye evaluations are cost effective and can create health care savings for both government and society as a whole. It then follows that solid intervention and screening plans be put into place. We have known this for at least a decade, however successful screening rates are still beyond our reach. It is important that we identify the disconnect and try to fix it. On the one hand, perhaps rates are low because screening isn't high on the priority list of the typical indemnity insurer. On the other, we do know that exams that don't lead to treatment are costly to everyone, so maybe better follow-through is the answer.

One segment that has gotten the message is the Health Care Financing Administration (HCFA), whose policies are often influential to other sectors of the health care arena. Their support of screening programs is significant, and it will have a huge impact on the way eye care is provided, if only via a simple trickle-down effect. HCFA's interest will no doubt effect positive change through non-radical, simple system alterations.

With regard to new technologies, we need to consider the benefits to the audience, the economic impact, and the costs.

Session IV

Lloyd Aiello, Joslin Diabetes Center

Telemedicine is a platform that can enable technology to work better for us, but it should not serve as a replacement for conventional medical evaluation. It can certainly provide access to care

in remote areas, and it may even promote self-interest in care on the patient side. But technological tools must be validated to existing standards of care, and there is still a need for patient education and improved compliance with existing guidelines.

Clinical trials will continue to play a role in telemedicine. We will need reading centers for trials and additional means of communication. It is important that we let our programs lead the technology effort and not let technology for its own sake drive the machine.

We also need to continue to investigate the challenges presented by various telemedicine programs. For example, we must keep up with technological advances such as image capture and quality, image transmission and costs, image reading and standardization, and image storage and costs. In addition, critical issues for telemedicine will involve reimbursement, licensure, legal issues, access, quality of care, and cost.



Appendix A: Workshop Agenda

workshop

Implementation of Screening and Eye Exams for Diabetic Retinopathy

February 27-28, 2001 – Bethesda, Maryland

sponsored by

Tuesday, February 27, 2001

8:00 – 8:30 Breakfast

Opening Session

Co-Chairs: Robert Goldstein, MD, *Chief Scientific Officer, JDRF*
Lloyd M. Aiello, MD, *Scientific Chair of Workshop, Joslin Diabetes Center*

8:30 – 8:45 Welcome and Introductory Remarks

Session I: Introduction to the Key Issues

Moderator: Jinan B. Saaddine, MD, MPH, *Centers for Disease Control and Prevention*

8:45 – 9:15	Current Practice in Screening and Eye Exams for Retinopathy: An Overview	Thomas W. Gardner, MD Pennsylvania State University
9:15 – 9:45	Patient Population and Patient-Physician Relationship Issues: An Overview	Emily Chew, MD <i>National Eye Institute</i>
9:45 – 10:15	Cost-Effectiveness Issues: An Overview	Jonathan Javitt, MD, MPH <i>Active Health Management</i>
10:15 – 10:45	Break	
10:45 – 11:15	Role of New Technology in Enhancing Patient Access to Eye Exams	Sven-Erik Bursell, PhD <i>Joslin Diabetes Center</i>
11:15 – 11:45	Speakers Panel: Questions, Answers, and Audience Discussion	
11:45 – 12:40	Lunch	

Tuesday, February 27, 2001 (continued)

Session II: Case Studies

Patient Population and Patient-Physician Relationship Issues

Moderator: Dan Stryer, MD, AHRQ

12:40 – 1:00	Perspectives on Care	Paul Lee, MD, JD <i>Duke University Medical Center</i>
1:00 – 1:20	Eye Exams and Their Relationship to the Progression of Microvascular Complications in a Cohort of African-Americans with Type 1 Diabetes	Monique Roy, MD <i>New Jersey Medical School</i>
1:20 – 1:40	Patient-Physician Relationships in a Diabetic American-Indian Population	Kelly J. Acton, MD, MPH, FACP <i>Indian Health Service</i>
1:40 – 2:00	Patient-Physician Relationships in a Diabetic Native Hawaiian Population	Marjorie Mau, MD <i>University of Hawaii</i>
2:00 – 2:20	Strategies for Bringing Retinopathy Screens and Follow-Up Eye Exams to Inner-City Populations	Robert N. Frank, MD <i>Wayne State University</i>
2:20 – 2:40	Demographic Features Predicting Compliance with Recommendations for Annual Retinal Examinations	Edward B. Feinberg, MD, MPH <i>Boston University</i>
2:40 – 3:00	A Best-Case Scenario: A Hypothetical Patient's Optimal Clinical Management to Prevent Progression of Retinopathy	Ronald Klein, MD, MPH <i>University of Wisconsin</i>
3:00 – 3:30	Break	
3:30 – 4:00	Speakers Panel: Questions, Answers, and Audience Discussion	

Session III: Case Studies

Cost-Effectiveness Issues

Moderator: Richard Eastman, MD, *Cygnus, Inc.*

4:00 – 4:20	Eye Exams for Diabetic Retinopathy as a Performance Measure of Quality: Findings from a Local Practice Improvement Project	John Oh, MD, MPH <i>KePRO</i>
4:20 – 4:40	Using Health Economic Information to Inform Health Policy and Decisions	Erik J. Dasbach, PhD <i>Merck Research Laboratories</i>
4:40 – 5:00	A Public-Private Partnership to Increase Eye Exam Rates for Medicare Beneficiaries with Diabetes	Barbara B. Fleming, MD, PhD <i>Health Care Financing Administration</i>
5:00 – 5:30	Speakers Panel: Questions, Answers, and Audience Discussion	

Dinner hosted by Eli Lilly and Company

Tragara Ristorante, 4935 Cordell Avenue, Bethesda (301) 951-4935

7:00 – 7:30	Social hour
7:30	Dinner

Wednesday, February 28, 2001

7:45 – 8:15 Breakfast

Keynote Presentation

8:15 – 9:00 **Improving the Care of Patients with Diabetes**
Frederick Ferris, MD, *National Eye Institute*

Session IV: Case Studies

Role of New Technology in Enhancing Patient Access to Eye Exams

Moderator: Lloyd M. Aiello, MD, *Joslin Diabetes Center*

9:00 – 9:20	Implementation of Telemedicine Evaluation of Diabetic Retinopathy in a Prison Setting	Helen K. Li, MD <i>University of Texas Medical Branch</i>
9:20 – 9:40	Value = Quality/Cost: The Value of Telemedical Diabetic Retinopathy Evaluation	Stephen R. Fransen, MD <i>Inoveon Corp.</i>
9:40 – 10:00	Telemedicine-Based Diabetic Retinopathy Screening in the American Indian Community in California	Heather Bernikoff, MS <i>California Telehealth and Telemedicine Center</i>
10:00 – 10:30	Speakers Panel: Questions, Answers, and Audience Discussion	
10:30 – 11:00	Break	

Session V: Summary

Moderator: Lloyd M. Aiello, MD, *Joslin Diabetes Center*

11:00 – 11:30	What Have We Heard? 10-Minute "Reporter" Summaries from Session Moderators	
11:30 – 12:00	Audiencewide Discussion of Key Priorities/Recommendations	
12:00 – 12:15	Concluding Remarks	Lloyd M. Aiello, MD <i>Joslin Diabetes Center</i> Robert Goldstein, MD <i>JDRF</i>
12:15	Lunch available	

Postworkshop

Developing Workshop Recommendations

Moderators: Robert Goldstein, MD, *JDRF*
Daniel B. Stryer, MD, *AHRQ*

1:30 – 3:30	A select working group, including sponsors and other agency representatives, will meet to review the workshop's findings and translate them into recommended "action items" for health research and policy organizations.
-------------	---

☒ Appendix B: Workshop Participants

Kelly J. Acton, M.D., MPH, FACP
Director, IHS National Diabetes Prgm
CAPTAIN, U.S.P.H.S.
5300 Homestead Road, NE
Albuquerque, NM 87110
Tel: 505-248-4182
Fax: 505-248-4188
kelly.acton@mail.ihs.gov

Lloyd M. Aiello, M.D.
Beetham Eye Institute
Joslin Diabetes Center
1 Joslin Place
Boston, MA 02215
Tel: 617-732-2520
Fax: 617-264-2776
lloyd.m.aiello@joslin.harvard.edu

David J. Arthur
Marketing Manager
Eli Lilly and Company
Lilly Corporate Center
Indianapolis, IN 46285
Tel: 317-433-4595
Fax: 317-277-1394
djarthur@lilly.com

Heather Bernikoff, M.S.
California Telehealth & Telemedicine
Center
1215 K Street, Suite 800
Sacramento, CA 95814
Tel: 916-552-7687
Fax: 916-552-7526
hbernikoff@calhealth.org

George W. Blankenship, M.D.
640 Olde Ventura Farm Rd.
Hershey, PA 17036
Tel: 717-533-1354
Fax: 717-761-5604
blankenship@supernet.com

Lois Book, R.N., M.S., Ed.D.
American Association of Diabetes Educators
Director of Professional Relations
100 West Monroe Street, Suite 400
Chicago, IL 60603
Phone: 312-424-2426, ext. 820
Fax: 312-424-2427
Lbook@aadenet.org

Norma Bowyer, O.D., MS, MPH, FAAO
244 Wagner Road
Morgantown, WV 26501
Tel: 304-291-5051
bowyer@earthlink.net

MaryBeth Branigan
Research Triangle Institute
3040 Cornwallis Rd.
Research Triangle Park, NC 27709-2194
Tel: 919-541-5661
Fax: 919-541-6121
branigan@rti.org

Susan Brown
Research Triangle Institute
3040 Cornwallis Road
PO Box 12194
Research Triangle Park, NC 27709-2194
Tel: 919-541-7401
Fax: 919-541-6221
seb@rti.org

Sven-Erik Bursell, Ph.D.
Director of Eye Research
Beetham Eye Institute
Joslin Diabetes Center
1 Joslin Place
Boston, MA 02215
Tel: 617-732-2583
Fax: 617-732-2545
Sven.Bursell@joslin.harvard.edu

Jerry Cavallerano, O.D., Ph.D.

Assistant to the Director
Beetham Eye Institute
Joslin Diabetes Center
One Joslin Place
Boston, MA 02215
Tel: 617-732-2554
Fax: 617-264-2776
jerry.cavallerano@joslin.harvard.edu

Emily Chew, M.D.

Division of Epidemiology and Clinical
Research
NEI, NIH
Building 31, Room 6A52
31 Center Drive, MSC 2510
Bethesda, MD 20892-2510
Tel: 301-496-6583
Fax: 301-496-2297
echew@nei.nih.gov

Erik J. Dasbach, Ph.D.

Merck Research Laboratories
10 Sentry Parkway, BL2-3
Blue Bell, PA 19422
Tel: 610-397-2658
Fax: 610-397-3855
erik_dasbach@merck.com

Peter Dudley, Ph.D.

National Eye Institute
Building 31, Room 6A52
31 Center Drive MSC 2510
Bethesda, MD 20892-2510
Tel: 301-496-0484
pad@nei.nih.gov

Richard C. Eastman, M.D.

Cygnus, Inc.
400 Penobscot Drive
Redwood City, CA 94063
Tel: 650-599-2548
Fax: 650-599-2519
Reastman@cygn.com

Kate Eltzroth

Telemedicine and Advanced Technology
Research Center
Building 1054
Patchel Street
Ft. Detrick, MD 21702-5012
Tel: 301-619-7925
Fax: 301-619-7914
eltzroth@tatrc.org

Priscilla Enriquez

California Telehealth & Telemedicine
Center
1215 K St., Ste. 800
Sacramento, CA 95814
Tel: 916-552-7674
Fax: 916-552-7526
Penriquez@calhealth.org

Edward B. Feinberg, M.D., MPH

Department of Ophthalmology
Boston University School of Medicine
67 Meadowbrook Road
Brookline, MA 02445
Tel: 617-734-6507
Fax: 617-734-7558
ebfeinberg@att.net

Frederick Ferris, M.D.

National Institutes of Health
Building 31, Room 6A52
31 Center Drive MSC 2510
Bethesda, MD 20892-2510
Tel: 301-496-6583
Fax: 301-496-2297
RickFerris@nei.nih.gov

Barbara Fleming, M.D., Ph.D.

Senior Medical Officer
HCFA
DHHS/HCFA/OA/OCSQ/PMG
Baltimore, MD 21244-1850
Tel: 410-786-6863
bfleming@hcfa.gov

Judith E. Fradkin, M.D.
Director
Division of Diabetes, Endocrinology
and Metabolic Diseases
NIDDK, NIH
Building 31, Room 9A16
31 Center Drive MSC 2560
Bethesda, MD 20892-2560
Tel: 301-594-8814 or 301- 496-7349
Fax: 301-480-3503 or 301-480-6792
FradkinJ@extra.niddk.nih.gov

Robert N. Frank, M.D.
Kresge Eye Institute
Wayne State University School of Medicine
4717 St. Antoine Boulevard
Detroit, MI 48201
Tel: 313-577-7613
Fax: 313-577-8884
rnfrank@med.wayne.edu

Stephen R. Fransen, M.D.
Inoveon Corporation
800 N. Research Parkway, Suite 370
Oklahoma City, OK 73104-3698
Tel: 405-271-9025
Fax: 405-271-9026
stephen-fransen@inoveon.com

Joanne Gallivan
Director
National Diabetes Education Program
NIDDK
National Institutes of Health
Building 31, 9A04
31 Center Drive
Bethesda, MD 20892
Tel: 301-496-6110
Fax: 301-496-7422
joanne_gallivan@nih.gov

Thomas W. Gardner, M.D., M.S.
Penn State University College of Medicine
500 University Drive
Hershey, PA 17033
Tel: 717-531-8783
Fax: 717-531-5475
tgardner@psu.edu

Dr. Sanford A. Garfield
NIDDK, NIH
Building 31
31 Center Drive
Bethesda, MD 20892
garfields@ep.niddk.nih.gov

Gilman Grave
CRMC
National Institute of Child Health
and Human Development
National Institutes of Health
6100 Executive Blvd., Room 4B11
Rockville, MD 20892-7510
Tel: 301-496-5593
Fax: 301-480-9791
gg37v@nih.gov

Margaret Himelfarb
116 Taplow Road
Baltimore, MD 21212
Tel: 410-532-7224
Fax: 410-532-7910
himelfarbM@aol.com

Rosemary Janiszewski, M.S., CHES
Deputy Director, Office of Communication
Health Education and Public Liaison
National Eye Institute, NIH
Building 31, Room 6A32
31 Center Drive MSC 2510
Bethesda, MD 20008
Tel: 301-496-5248
Fax: 301-402-1065
rjaniszewski@nei.nih.gov

Jonathan Javitt, M.D., MPH
Active Health Management
3 Bethesda Metro Center
Suite 100
Bethesda, MD 20814
Tel: 301-951-5306
Fax: 301-654-8996
jjavitt@e-medx.com

Richard Kahn, Ph.D.
Chief Scientific and Medical Officer
American Diabetes Association
1660 Duke Street
Alexandria, VA 22311
Tel: 703-299-2065
Fax: 703-836-7439
rkahn@diabetes.org

Ronald Klein, M.D., MPH
Department of Ophthalmology and Visual Sciences
610 North Walnut Street, 460 WARF
Madison, WI 53705-2397
Tel: 608-263-7758
Fax: 608-263-0279
Kleinr@epi.ophth.wisc.edu

Carrie Kovar
American Academy of Ophthalmology
Governmental Affairs
1101 Vermont Avenue, N.W., Suite 700
Washington, D.C. 20005
Tel: 202-737-6662
Fax: 202-737-7061
ckovar@aaodc.org

Paul Lee, M.D., J.D.
Duke University Medical Center
Department of Ophthalmology Glaucoma Service
Box 3802, DUMC
Durham NC 27710
Tel: 919-681-2793
Fax: 919-681-8267
lee00106@mc.duke.edu

Helen K. Li, M.D.
University of Texas Medical Branch
Department of Ophthalmology and Visual Sciences
301 University Boulevard
Galveston, TX 77555-0787
Tel: 409-772-8108
Fax: 409-772-2928
hli@utmb.edu

Barbara Linder, M.D., Ph.D.
Program Director
Clinical Endocrinology and Diabetes Complications
Division of Diabetes, Endocrinology and Metabolic Diseases
NIDDK, NIH
6707 Democracy Blvd., Room 699
Bethesda, MD 20892-5460
Tel: 301-594-0021
Fax: 301-480-3503
LinderB@extra.niddk.nih.gov

Marjorie Mau, M.D., M.S.
University of Hawaii
Department of Medicine
1356 Lusitana Street, 7th Floor
Honolulu, HI 96813
Tel: 808-586-2910
Fax: 808-586-7486
mmau@hawaii.edu

Jack A. McLaughlin, Ph.D.
Acting Director
National Eye Institute
Bldg. 31, Room 6A05
31 Center Drive, MSC 2510
Bethesda, MD 20892-2510
Tel: 301-496-4583
jmclaughlin@nei.nih.gov

Leanne McNamee
Manager, Healthcare Practice
Burson-Marsteller
1801 K Street, NW
Washington, DC 20006
Tel: 202-530-4694
Fax: 202-530-4500
Leanne_McNamee@was.bm.com

Sara Milo
Alliance for Eye and Vision Research
426 C Street, NE
Washington, DC 20002
Tel: 202-543-1604
Fax: 202-543-2565
sm@capitolassociates.com

John Oh, M.D., MPH
KePRO
353 Markle Drive
PO Box 8315
Harrisburg, PA 17105-8315
Tel: 717-564-8288 x2634
Fax: 717-564-5068
pa2pro.joh@sdps.org

Monique Roy, M.D.
University of Medicine and Dentistry
New Jersey Medical School
Department of Ophthalmology
90 Bergen Street, Suite #6100, D.O.C.
Newark, NJ 07103
Tel: 973-972-2036
Fax: 973-972-2068
roymo@umdnj.edu

Megan Pace
Senior Associate, Ally Development
Government Relations
Eli Lilly and Company
555 12th Street, NW, Suite 600
Washington, DC 20004
Tel: 202-434-1035
Fax: 202-393-7960
mpace@lilly.com

John Ruffin, Ph.D.
Director
National Center on Minority Health and
Health Disparities
Building 1, Room 260B
1 Center Drive, MSC 0164
Bethesda, MD 20892-0164
Tel: 301-402-1366
ruffinj@od.nih.gov

Matt Petersen, M.D.
Director, Research Programs
American Diabetes Association
1701 N. Beauregard Street
Alexandria, VA 22311
Tel: 703-299-2071
Fax: 703-549-1715
mpetersen@diabetes.org

Jinan B. Saaddine, M.D. M.P.H.
Medical epidemiologist
MPHNCCDPHP/DDT
4770 Buford Hwy, NE (K-68)
Atlanta, GA, 30341-3717
Tel: 770- 488-1274
Fax: 770-488-1148
Jsaaddine@cdc.gov

Ronald K. Poropatich, M.D.
Chief, Telemedicine Directorate
Walter Reed Army Medical Center
Building 2, Ward 64, Room 6444
Washington, DC 20307-5001
Office: 202-782-8935
Fax: 202-782-4669
ron.poropatich@na.amedd.army.mil

William T. Schmidt
Vice President of Public Affairs
JDRF
1400 I Street, NW, Suite 530
Washington, DC 20005
Tel: 202-371-9746
Fax: 202-371-2760
bschmidt@jdrf.org

Colleen Reilly
P.O. Box 5517
Washington, DC 20016
Tel: 202-363-6981
Fax: 202-363-3204
creils@aol.com

John A. Shoemaker
Assistant Vice President
Research and Public Policy
Prevent Blindness America
500 East Remington Road
Schaumburg, IL 60173
Tel: 847-843-2020
Fax: 847-843-8458
JShoemaker@PreventBlindness.org

Allen M. Spiegel, M.D.
Director, NIDDK, NIH
Building 31, Room 9A52
31 Center Drive MSC 2560
Bethesda, MD 20892-2560
Phone: 301/496-5877
Fax: 301/402-2125
SpiegelA@extra.niddk.nih.gov

Daniel B. Stryer, M.D.
Center for Outcomes and Effectiveness
Research
Agency for Healthcare Research and Quality
6010 Executive Blvd., Suite 300
Rockville, MD 20852
Tel: 301-594-4038
Fax: 301-594-3211
dstryer@ahrq.gov

Eugene Trinh
NASA Headquarters, Code UG
300 E Street SW
Washington, DC 20546
Tel: 202-358-0649
Fax: 202-358-3091
etrinh@hq.nasa.gov

Judith L. Vaitukaitis, M.D.
Director, NCRR, NIH
DHHS
Public Health Services
Building 31, Room 3B11, MSC 2128
Bethesda, MD 20892-2128
Tel: 301-496-5793
Fax: 301-402-0006
vaitukaitis@nih.gov

Louis Skip Vignati
Eli Lilly and Company
Lilly Corporate Center
Indianapolis, IN 46285
Tel: 317-276-9685
Fax: 317-277-1234
Vignati_Louis@Lilly.com

Thomas Ward
Ophthalmology Service
Walter Reed Army Medical Center
6900 Georgia Avenue, NW
Washington, DC 20307-5001
Tel: 202-782-8600
Fax: 202-782-6156
thomas.ward@na.amedd.army.mil

John Whitener, O.D.
American Optometric Association
1505 Prince Street, #300
Alexandria, VA 22314
Tel: 703-739-9200
Fax: 703-739-9497
amptcor@aol.com

C. Pat Wilkinson, M.D.
Chair, Department of Ophthalmology
Greater Baltimore Medical Center
Professor, Dept. of Ophthalmology
Johns Hopkins University
Physicians Pavilion, Suite 505/West
6569 N. Charles St.
Baltimore, MD 21204
Tel: 410-828-2196
Fax: 410-828-2648
cwilkins@gbmc.org

Daniel Winfield
Research Triangle Institute
PO Box 12194
Research Triangle Park, NC 27709-2194
Tel: 919-541-6431
Fax: 919-541-6221
winfield@rti.org

Ran Zeimer, Ph.D.
Professor
Ophthalmic Physics Laboratory
Wilmer Eye Institute
Johns Hopkins University
600 North Wolfe Street
Baltimore, MD 21287-9131
Phone: 410-614-2900
rzeimer@jhmi.edu

JDRF Research Department Staff:

Office Location:

120 Wall Street, 19th Floor
New York, NY 10005

Tel: 212-785-9500

800-533-CURE

Fax: 212-785-9609

212-785-9595

Peter Van Etten

JDRF President & CEO

pvanetten@jdrf.org

Robert A. Goldstein, M.D., Ph.D.

Chief Scientific Officer

rgoldstein@jdrf.org

Jennifer Auerbach

Administrative Assistant

jauerbach@jdrf.org

Samar Burney, Ph.D.

Scientific Program Manager

Audrey Espenscheid

Research Manager

aespens@jdrf.org

Kim Hunter-Schaedle, Ph.D.

Associate Director of Research

khunter@jdrf.org

Jim Stallard

Science Writer